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ABSTRACT

This paper explores Canadian educational services offered to severely and profoundly handicapped children and comments on their cautious welcoming into the regular education system. School administrators must become familiar with the needs of severely handicapped students, and must become much more involved in the planning, support, and implementation of in-service or staff development activity. Student placement practices are changing as more severely and profoundly handicapped children are being placed in neighborhood schools, requiring a greater amount of an administrator's time in planning, facilitating, and coordinating the provision of services for all students. A transdisciplinary model of service delivery is suggested, which calls for teachers delivering all school-based services to students, while related service professionals assess and demonstrate to train the teacher. The individual educational program should take into account the person's total life circumstances and the values and wishes of the primary caregivers. Several issues need to be addressed to enhance the educational experience of the severely disabled student, including: transitions, case management, education and related services, teacher training, and exemplary practices. (JDD)

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The Education of Severely and Profoundly Handicapped Children and Youth: Some Issues That Currently Need to Be Resolved

by
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presented at

Canadian Symposium on Special Education Issues
Toronto, Ontario
on
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Preamble

Let me begin by sharing with you two stories. Happy stories.

Amanda is now seven years old. When she was born the medical people said that because of the severity of her disabilities she would die in two weeks. After two weeks had passed the family was told that she would die before she was two years of age. Today she is seven years of age, attending school daily in a K-12 school with 200 other students, and certainly the most severely disabled pupil in that school. She comes from a good home by any measure. In the first six months of school she has demonstrated an amazing ability and motivation to get around, and to communicate through gestures, grunts and other vocalizations. What will her educational experience be like in light of where she is going to school?

William is now fourteen years old. Shortly after he was born he was placed in a permanent foster home, requiring full-time care, only being able to move his head from side to side. Two months ago he was moved to a long-term Level IV Care facility. He attends school daily, and over the last six months a teacher has been teaching him how to communicate using Bliss, through the use of a computer, by pushing a Yes/No stick with his cheek. William has become surprisingly adept at learning the system. Recently he wrote his first independent sentence, "I am homesick." Several things are remarkable about this event. There is no such word as "homesick" on the Bliss system. He had to put two words/concepts together - "home" and "sick." Secondly, no one had really been aware of how much was going in - how much he had been learning over the years because of his inability to express himself.

These two youngsters are severely and profoundly disabled/handicapped. No one argues that. One of the low-key but persistent debates in education today asks the question: What is the extent and what are the limitations in our work with these children, these youth? Surely the limitations are not consistent with our easily preconceived notions. What is the extent to which we go in our involvement with these students? These two students are thriving in school because they have teachers who not only care, in the humanistic sense, but also pursue with a persistent vigour the development of skills, for example, in computer assisted instruction, in seeking information from other professions and keeping an open mind to any possibility, looking for any potentiality.

Before getting into the more formalized part of this presentation, some perspectives, parameters and caveats need be identified.

1. Organizers of this symposium wanted speakers to make reference to current and relevant research from a Canadian perspective, if possible! Well, it is possible and the literature is starting to appear. It is mostly descriptive. There appears to be some limited empirical research happening and reported in Canada as it affects the education of severely and profoundly handicapped children and those who work with them. So, this presentation reflects, in part, that literature.

2. The perspective being shared is from one who has actively worked from within the system, supporting schools and teachers and (mostly, it seems!) administrators in breaking new ground. Seeing many different situations, and having a perspective that crosses school division boundaries, provides the experiential base for what is in this presentation. Thus the issues that will be addressed are selective. You can collect whole libraries on the general topic. We can't cover them all!

3. A brief statement about who it is that we are talking about is in order. Even on the most simplest of criteria, human beings can be difficult to classify! Today, we are considering the child or youth who has limited expressive speech, or has extreme difficulty eating, dressing or toileting, or who can't get around without a wheelchair; or, usually an individual who has a combination of these characteristics. Mental retardation is frequently an accompanying characteristic. We tend to identify the disabled student from an educational perspective, i.e., can he write, talk, play with peers, rather than does he have cerebral palsy or Cornelia de Lange syndrome or spina bifida.

In many ways we are talking about Catherine in Nicola Schaefer's (1982) book, Does She Know She's There; or Norm Kunc (1981) in his book, Ready, Willing and Disabled.

Introduction

The education of children and youth who are severely and profoundly handicapped has become a topic of increasing interest to educators in Canada during the 1980s (Baine, 1984; Csapo & Baine, 1985; Csapo & Goguen, 1980; Forest, 1984; Marlett, Gall & Wight-Felske, 1984; Sobsey, 1985). The role of education and schools in the lives of these children and youth, and their families, continues to draw the attention of analysts assessing the continuing evolution of the larger human service system (Lord, 1985; Simmons, 1982).

Increasing concern on the part of educators in Canada was evident throughout the 1970s regarding the lack of access to services offered by organized education towards all handicapped children and youth (Ballance & Kendall, 1969; Commission on Emotional and Learning Disorders in Children, 1970; Csapo & Goguen, 1980; Treherne, Dice, Grigg & Sanche, 1974). Teachers' federations have developed more than a passing interest in the "mainstreaming" concept (Csapo, 1981; Federation of Women Teachers' Associations of Ontario, 1983; Saskatchewan Teachers' Federation, 1985). Recent federal public policy initiatives, particularly with respect to the Canadian Charter of Rights and Freedoms, has generated considerable interest in the community of Canadians particularly interested in the quality of lives of severely and profoundly handicapped persons (MacKay, 1984).

Thus a further exploration of this topic as a special education issue at this time appears quite appropriate.

In many quarters the perception continues that educators have always been cautious when confronted with a new challenge, and wanting to do the task appropriately if it was determined that it should be done under the supervision of the school. The Canadian experience of welcoming the severe and profoundly handicapped child into the regular education system certainly reflects the cautiousness of educators being confronted with new demands for which they may feel they have limited resources, are inadequately trained or prepared for the task ahead, or, just do not believe that these students belong in the mainstream of education (Forest, 1984). Underlying many of these reactions are attitudes counterproductive to the task at hand.

There still is no consensus in the literature on how to positively modify attitudes which presumably would enhance the quality of services available to these students (Barton, Snart & Hillyard, 1985; Donaldson, 1977; Towner, 1984; Winzer, 1985). As a general observation, it appears that over the last twenty years there has been slow but increasing acceptance by educators of their responsibility towards children and youth frequently classified as severely disabled. Does this reflect a change in attitude? There certainly has been a change in practice in those twenty years. Can one assume that educators will adjust to the presence of the child who is "deaf", "blind", "emotionally disturbed" or "trainable mentally retarded"? The following observation by Haring (1985) lends support for some optimism:

> In 1977, the Division on Mental Retardation of the Council for Exceptional Children published a volume, conceived and edited by Ed Sontag, entitled "Educational Programming for the Severely and Profoundly Handicapped." This volume has been one of the most widely disseminated and influential works of its kind in the history of special education. (p. i)

The very wide distribution of such a document reflects that it continues to meet a need out in the larger community.

Administration

With increasing frequency community schools are accepting the challenge of meeting the educational needs of these children and youth who are severely and profoundly handicapped despite equivocal research to support this thrust (O'Neill & DeBruyn, 1984). One major implication for the administrators in these schools is the need to bring some "background" to managing people, resources and issues that inevitably arise in these situations. School principals and system administrators today do not have, generally speaking, an experiential base in managing situations that included this type of student. They did not teach in environments where these children attended. In addition, there has not been much opportunity in Canada to obtain formal training in the administration of programs that are directed at children and youth who are severely and profoundly handicapped (Csapo & Baine, 1985; Dahl, 1985; Sonntag, 1982).

Csapo and Baine (1985) state it rather succinctly:

> To insure successful integration, not only within the school but also within the community, administrators need to be familiar with the nature of the handicap, the needs of the students with severe handicaps and the methods by which these needs can best be met by both school and community. Programs are also required to train school psychologists, occupational, physical, and speech therapists, social workers, lawyers, nurses, physicians and dentists to meet the needs of students with severe handicaps and assist them to function within natural community environments. (p. 130)

Children and youth who are disabled are no longer, or, much less frequently, congregated in larger institutional settings. Frequently the training programs of future professionals reflect service delivery patterns of past eras. The updating and/or expanding of undergraduate or graduate training programs in Canada to include a focus on administrative issues as they pertain to this group of students with very challenging learning needs is long overdue.

Another facet of the work of administration is the need for administrators in special education to become much more involved in the planning, support, and implementation of in-service or staff development activity (Berreth, Beatty & Burrello, 1982). Many of the issues and practices identified in this paper reflect the need for continuing efforts to provide staff with the training and opportunity for new experiences to enhance the growth we wish to see in qualitative improvement in educational programs for students who are severely and profoundly handicapped.

Placement Practices

The placement of students in programs where the objective is to meet the educational needs of these students has become the focal point for much debate. Traditionally these students did not receive services in neighborhood schools. New practices are emerging.

Data from one province with which the writer is most familiar clearly indicates that many more educational leaders are now involved in the day-to-day management of programs for these students (see Appendix A).

As this data shows, the number of pupils who are severely and profoundly handicapped and attending school in segregated settings has remained fairly static in Saskatchewan since 1978, when the Saskatchewan Department of Education was given administrative responsibility for programs for multiple handicapped students. These programs had previously been operated under the mandate of Saskatchewan Social Services. Students and their parents having come into the system since that time have obviously exercised a greater number of options in terms of placement. In many rural areas, these students have begun attending the community school, frequently at the insistence

of parents who were not prepared to move them to congregated programs outside of their immediate communities. For the last three or four years, many of the children entering the education system have been obtaining home-based services through the Early Childhood Intervention Programs. The knowledge that the parents of these students have acquired about their children's development, combined with a set of expectations developed through more systematic involvement with human service diagnostic and assessment agencies and related service providers, has translated into strong advocacy on behalf of the child by the parents and preschool support services. Thus school systems have been hard pressed to maintain traditional placement practices. In turn, the rhetoric picked up by the media, advocacy groups and the parents themselves regarding normalization, integration and mainstreaming is today having its impact felt in virtually every school in our society.

A great amount of an administrator's time is spent in planning, facilitating and coordinating the provision of services and supervision of ongoing services for all students. The decision to place a child or a group of children who are severely and profoundly handicapped in a neighborhood school gives rise to new dynamics that frequently have not been experienced heretofore by the staff in those locations.

By the very nature of the child that now enters the school, a number of different professionals have become part of the action. Frequently they are employed by different agencies or departments of government. They are part of the human service system. They work under different administrative rules, adhere to their profession's codes of ethics and standards of professional practice with which educators are unfamiliar. The agencies they work for frequently respond to new demands for service emanating elsewhere in the human service system. Thus, how we as educators are to provide the continuity and predictability of quality service in this arena is of increasing concern. In the United States the issue of the provision of related services has led to a number of legal tests. The judgements of the courts provide no clear direction or emerging consensus about the place of related services in education (Lehr & Haubrich, 1986). Since policies and practices at one level of enterprise depend on the policies and practices at other levels of governance, a shift in policy or practice anywhere in the system will have a ripple effect. When viewed from the perspective of a decade ago, as an example, the change in policy in the mid 1970s by Saskatchewan Social Services, whereby there were to be zero admissions of children to the provincial institution that had traditionally served individuals who were severely and profoundly handicapped, has had a continuing, occasionally unsettling, impact in local communities across the province. This impact has been felt throughout the human service system, not just organized education.

Human service system administrators, including educational administrators, who did not or have not picked up on the philosophical winds of change underlying these changes in practice and policy frequently find themselves subject to inordinate pressures from the community, their staff and, occasionally, their superiors.

One aspect of the infrastructure that supports educational programming for these students relates to the need to coordinate support services at the school level.

A recent major review of curriculum and instruction in Saskatchewan identified the critical aspect of this need in its final report, Directions (1984):

> When children come to school with needs which impede learning, teachers have little recourse but to attend to those needs. Without support services, the task is prohibitive.
>
> There is currently no one person or agency who works with parents and providers of services to see that all needs of a child are met, and to ensure that services are not overlapping or working at cross-purposes. Perhaps the most important observation that the Committee made was that, unless these services are coordinated at the local level, and unless people are involved in decision-making, the services will probably not be of benefit to those who need them. (p. 22)

Leadership efforts need to be directed at coordinative activities that cross services, cross agencies and cross levels of responsibility. The need to focus these efforts at the school level should certainly be a priority. Having the most up-to-date information on how to access services and availability of services is much more feasible given current capabilities in the electronic transmission of information and data.

How the required service is delivered in a given setting is another issue. Frequently severely and profoundly handicapped children need to engage in activities that traditionally have been monitored, even delivered, by many different professions, such as speech pathologists, physiotherapists, occupational therapists, social workers, and others. Baine & Sobsey (1983) have identified the transdisciplinary model as a conceptual frame of reference, which suggests that students, while in school, receive what they need exclusively through the teacher. Related service professionals assess and demonstrate, but the day to day instruction and implementing of the recommendations are carried out by the teacher - at least that which can be done in the school context.

The transdisciplinary model should facilitate greater continuity and practicability and provide a more coherent, less disjointed approach to the student's program and progress than that experienced under interdisciplinary or multidisciplinary models.

Planning the Individual Educational Program

Planning an individual educational program for children and youth who are severely and profoundly handicapped cannot be done without taking into account that person's total life circumstance and the values and wishes of the primary caregivers (i.e., the parents). We may have heard of the six hour retarded child. The population we are discussing today presents needs that can only be met most effectively when taking into account a twenty-four hour perspective.

There is an immediacy to what the child or youth needs to learn. Development of basic functional skills like communication, whether verbal or non-verbal, dressing, eating, toileting, movement, and so on, need to be addressed in the planning of the student's educational plan. The parents or other caregivers have a vital interest in the training of these skills, keeping in mind the eighteen hours a day the child is not in school. Obviously the planning of a program for such a student need involve, directly, the student, parents, other caregivers and the myriad of support professionals who are part of the service delivery system as it regards a particular student (Cypher, et al., 1984). It appears that many more educators need much more experience in integrating educational oriented planning with the type of planning advocated by Green-McGowan and Kovacs (1984). This relationship will not be easily established on a systemic basis, though we now find an occasional school principal who enthusiastically supports it, seeing the short, medium and long term benefits to the student and his community.

Despite the fact that the vast majority of professionals and service agencies are congregated in urban areas, and despite the fact that rural areas have lagged behind in gaining easy access to the array of services frequently needed, due to a lack of qualified personnel, lack of comprehensive support services, and the difficulties encountered in coordinating geographically dispersed services (Helge, 1981; Singer, Close, Irvin, Gersten & Sailor, 1984), it is in rural areas where breakthroughs are being made in the type of comprehensive based planning and follow through envisaged here (Wheatlands, 1985). Consumer awareness of the possibility of such approaches and satisfaction with the outcome of individual planning efforts should encourage educators at all levels. The interface between a system's approach to program planning and delivery, and the planning around the unique strengths and needs of individuals continues to create tension in organized education. It seems to the writer that the continuing interaction between these two approaches to planning may be the vehicle whereby organizations and programs begin to develop the flexibility required in responding appropriately to human need.

Some Conclusions

Several issues need to be addressed in a direct and forthright way in order to enhance the quality of experience of the severely disabled student, and, to enhance the further evolution of our part of the human service delivery system.

1. Transitions: Schooling cannot occur in isolation for these students. The students are part of a larger community and all schools are part of that community. One transition point that requires facilitation and close monitoring is the transition from preschool services to school based services. Going to school is not a choice in Canada. Because school attendance is mandated by law, school systems are given certain responsibilities, for example, the power to organize programs and services with the resources available to them. Meeting individual needs in this context as these needs are currently understood has become a major challenge to school systems.

A second transition point is the transition from public school to post secondary education programs or other adult services. Certainly the role of the parent changes through this period. The person who is severely and profoundly handicapped becomes an adult in his own right just as other young people do. This transition is also frequently very difficult for the teacher. Educators have always been concerned about how ready their charges are for what lies beyond the relatively sheltered environment of the school.

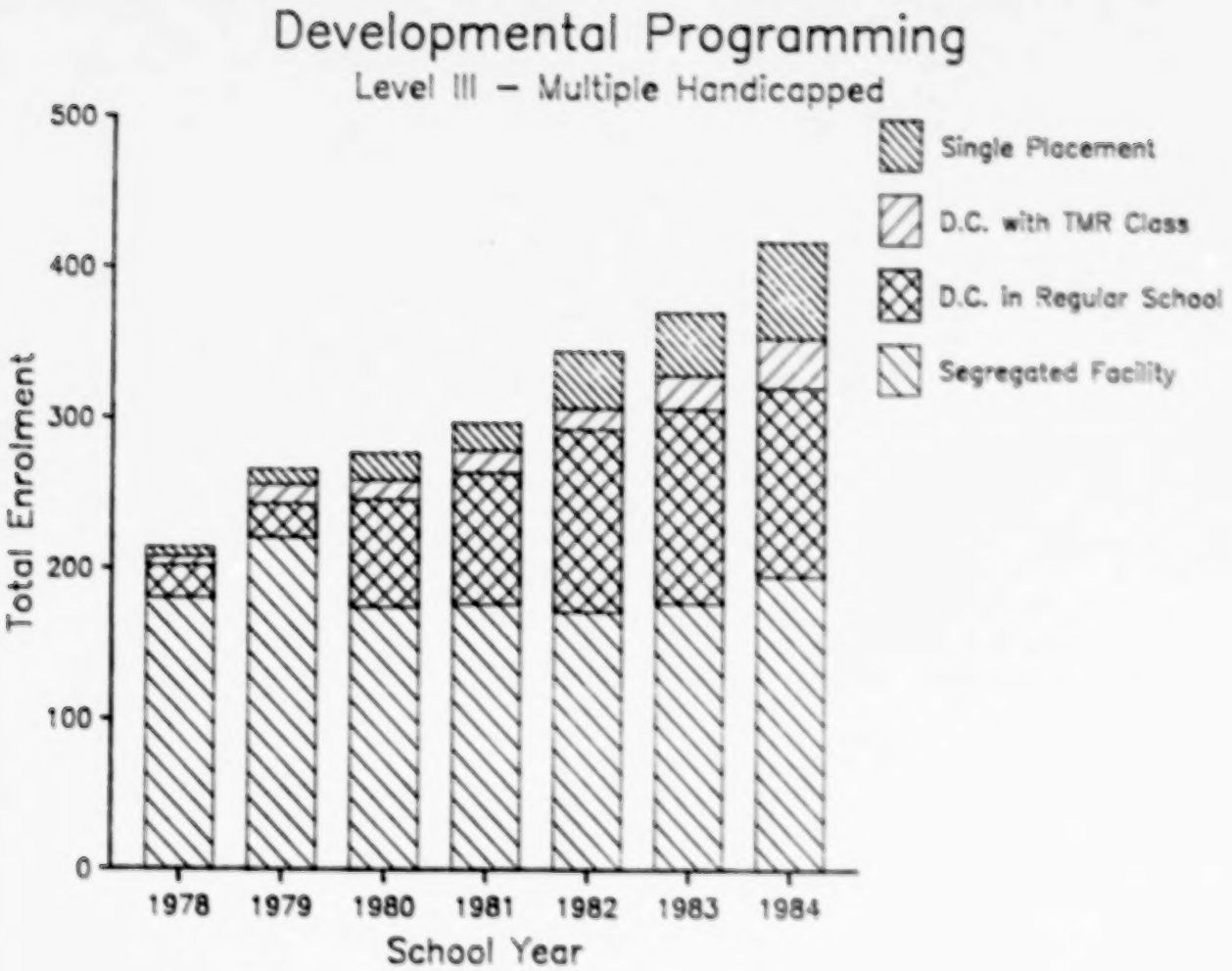
2. Case management: Who, in organized education, is responsible for seeing to it that all the right things occur for a given student? Is it the teacher aide, teacher, principal, consultant, and/or administrator? How can consumers be helped in understanding the shared nature of responsibility in education? In addition, as discussed earlier, many different professionals and agencies frequently have a legitimate stake in the ongoing care and development of the disabled individual. How can we, in education, better manage this function?

3. Education and related services: Traditional lines are becoming increasingly blurred when we try and differentiate "education" and "therapy." Community based service systems has come to mean services being provided in milieu, rather than in a clinic. Perhaps the issue of where children receive services needs to be re-examined in light of the development of the transdisciplinary model of utilizing support/related services.

4. Teacher training: All teachers are required to develop greater sensitivity to the myriad of issues that arise if these students are to be served in community schools. This certainly has implications for the pre-service training of teachers. Intensive training programs for special education teachers at both the undergraduate and graduate levels need to reflect the changes addressed in this paper.

5. Exemplary practices: For several years, the Council of Administrators of Special Education, Incorporated (1981, 1982, 1983) published examples of peer nominated exemplary practices. We need, in this country, to utilize or create structures that will identify and disseminate information about exemplary programs and practices. Exemplary programs and practices exist in Canada. Given the pluralistic nature of emerging values and beliefs regarding programming for severely and profoundly handicapped children and youth,

educators need to observe existing programs and create new programs and practices that are responsive to changing community values and beliefs. Given the current political climate regarding special education issues, educators need to draw on the resources and experiences from a wide array of practitioners.


Developmental Programming
Level III – Multiple Handicapped
Total Enrolment
500
400
300
200
100
0
1978
1979
1980
1981
1982
1983
1984
School Year
Single Placement
D.C. with TMR Class
D.C. in Regular School
Segregated Facility

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